

**Abstract 422**

**TITLE:** Successful Implementation of an HIV Surveillance System through Government and Community Collaboration

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**ISSUE:** Recent changes in the Massachusetts HIV/AIDS epidemic, including improvements in therapy and clinical stability, were catalysts for implementing an HIV surveillance system. It was important to the Massachusetts Department of Public Health (MDPH) to develop a system that addressed community concerns while providing scientifically sound data, which, in turn, would establish the basis of future HIV/AIDS public health endeavors. To reach this goal, a diverse HIV Surveillance Implementation Team (HSIT) investigated various reporting systems and made recommendations to MDPH.

**SETTING:** Commonwealth of Massachusetts

**PROJECT:** MDPH was committed to an inclusive process to develop an HIV surveillance system, convening an exploratory task force of staff, members of the statewide Consumer Advisory Board (CAB) and Massachusetts Prevention Planning Group (MPPG) and providers from community-based organizations (CBOs). The task force examined name and nonname HIV surveillance systems. To better understand the implications of each, site visits were made to two states—New Jersey (names) and Maryland (non-name). Findings were presented to the CAB and MPPG who subsequently recommended a non-name system. To successfully develop this system MDPH convened the HSIT. The HSIT is a multidisciplinary team of experts including epidemiologists, lawyers, physicians, data specialists, consumers, direct care providers and MDPH staff. The team's responsibility was to identify a non-name system that could provide valid data and address community concerns. Community meetings were held throughout the commonwealth to identify local attitudes and concerns about a non-name system. Issues raised included security, confidentiality and the possibility that reporting would create obstacles to seeking care. Providers participated in focus groups. Provider concerns included increased workload, patient distrust, security and adherence to confidentiality laws. Findings from these events provided the foundation of an HIV surveillance system in which reporting responsibility lies with clinical providers who would generate a code based upon data, which will allow for minimal duplication of cases. Recommendations were presented to and approved by the Commissioner of Public Health and the Public Health Council. Implementation began in January 1999. The HSIT will receive periodic reports from MDPH regarding implementation and provide community feedback.

**RESULTS:** Collaboration between the MDPH and the community led to the development of a non-name surveillance system which meets the Department's needs and addresses community concerns. Community representatives have been included in all aspects of development, implementation and follow-up. Successful implementation of the Massachusetts HIV surveillance system is largely attributed to engaging consumer and provider support in a participatory educational process.

**LESSONS LEARNED:** Our experience suggests that effective collaboration can be achieved and should be considered by states considering HIV surveillance systems.

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